Surviving Cogworld?

Supporting People with Developmental Disabilities In a Mechanistic System

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DD **Network**

DD Network

The mission of the Developmental Disabilities Network is to inspire, inform, and point the way to best practice of daily support for people with developmental disabilities and to promote greater opportunities for people with developmental disabilities to:

- **Contribute** to community life
- **Control** their own lives
- **Secure** good health and a stable home
- **Work** and earn an income
- **Learn** and grow

This paper was commissioned by a Wisconsin network and is anchored in my view of the development of services in that state but it may have application in other places.

I highlight interlocking trends in managing our system of assistance for people with developmental disabilities that worry me deeply. The extent to which I am troubled shows in the argumentative tone of the paper, which is written as a position to initiate debate.

I am arguing against trends produced by the whole long term-care system. The managers who accelerate these trends are responding to demands shaped by the whole system, which includes me, people with developmental disabilities and their families and advocates as well as a political system that is unable to engage the adaptive challenges posed by growing numbers of people who require long terms assistance and a society in flight from difference and interdependence. It is not a matter of fixing blame on a few interfering bureaucrats or politicians with a hostile agenda but of all of us assuming responsibility for establishing a balance of relationship and transaction that will sustain good support.

I think part of the trouble comes from a way to think about personal assistance whose consequences have come to seem inevitable. The made-up word "cogworld" is a device to make a taken for granted mindset odd enough to discuss.

This paper ends with questions. I have no solution to the difficulties I identify other than the invitation to join in figuring out how to make progress in a troubled environment.

Good Support is built on good relationships

Good relationships form the foundation of good support for people with developmental disabilities and their families. Policies and organizational practices that recognize this will be effective at offering support for good lives.

People with developmental disabilities who live good lives speak about the importance of good relationships with at least some of the paid people who assist them. They often choose words that reflect close relationships –"friend", "like family"– to describe their relationship with some assistants.

Cindy

Mary Beth has been with me 20 years. I don't think I would be where I am without Mary Beth. She has been with me the longest. Regardless of the ups and downs with the whole thing, she's there for me. Always. She helps me the best she can. She gets me to Special Olympics. She's just like a family member …she's my family …some of my family.

People who provide good direct support and stick with people with developmental disabilities speak of themselves in a mutual relationship with those they assist. They not only provide assistance for the person's growth, they learn and grow themselves.

Anna

I had never been around someone like Rebecca who wasn't able to respond to me in words. Someone who physically couldn't move in a way that would show me her interests or passions for things. So it was a real learning process for me. I didn't know what to expect.

I think at the time I very much felt like I was doing Rebecca a favor, that I was helping her. I've come to see that it's Rebecca who has pushed me on to do all the things that we have done together. She encourages me to be a better person in everything that I do. So even when we're not together her presence is with me and I bring that to each encounter that I have.

Rebecca

Good support workers understand what matters to the person they support and feel proud of amplifying the person's voice at times when that is important.

Bonnie

[The doctor] said, "I think it's time to look at assisted living for Donald. He's 80 years old. He's had a few falls."

And I told the doctor, 'I'm going to tell you what Donald just said to your nurse. She asked him if he had any children. Donald said, 'Not yet.'" His glass is still half full."

The doctor laughed and said, "We'll talk about this."

So he agreed, we'll do whatever we can to have Donald [continue to] live in his own home.

This place is alright.

Donald

People with developmental disabilities need assistance with everyday matters. Some people need assistance to eat and get dressed and get around. Some people need assistance with self-regulation when anxiety could take over. Some people need assistance with keeping their home and work life together. Good support is more than just doing tasks a person needs done. It is providing assistance in a relationship that recognizes a whole person, respects that person's dignity and encourages that person to live a good life.

Good support relationships have purpose that reach beyond the relationship. In collaboration with the person they create everyday opportunities for the valued experiences that characterize a good life…
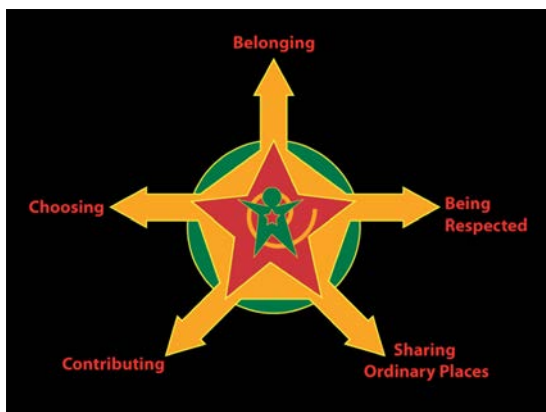
…belonging to the circles of personal relationship in which people enjoy and encourage one another.

…respect that comes from occupying valued social roles: worker, good neighbor, member.

…sharing the ordinary places and activities of a community's life.

…contributing by developing and offering personal gifts and capacities in ways that make a difference to others.

…choosing: expressing preferences and making decisions

Providing assistance is a job, usually funded with Medicaid money. Those who take the job agree to the terms of a transaction: agreed hours worked at a specific rate of pay (and sometimes other benefits); willingness to be guided by a plan and document its implementation; consent to follow policies and procedures. If assistance is simply a transaction with a capable person, people with developmental disabilities get authorized tasks done. If the person performing the task is respectful and friendly, the transaction will be pleasant. When competent assistance comes in the form of a good relationship, it becomes support for a good life.

Effective organizations invest in good relationships

Good support is not an accident and it cannot be bought for money. Good support engages whole people in each other's lives. It calls on the capacities of people's hearts, their practical thinking and their capacities for action. Organizations* that want people with developmental disabilities to have valued experiences invest in creating the conditions for good relationships to develop.

A good match. The more complex it is to build a relationship with a person with a developmental disability and their family, the more important it is to think about who will make the best fit. In general, the more influence the person and family have over the choice the better the chances of a good match.†

Time for relationship. Good support workers see themselves as playing a supporting role in a person's life story. Support workers need time with the person and those who know the person to learn the story and figure out how they can support the person as they author their next

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* As self-directed budgets become available, more people with developmental disabilities and their families are organizing supports for one person. These conditions are as important for these organizations for one as for those that assist large numbers.

† For a checklist of things to think about when matching people, see David Pitonyak & John O"Brien. *Matching Staff*. www.dimagine.com/Matching.pdf

chapter. They need the chance to become familiar with the daily rituals and cultural practices that are important to people and their families. They need to share time and experiences with the person to learn who they are and invite their trust by making and reliably keeping agreements. The more discouragement and trauma a person has experienced in past relationships, the more important this time is.
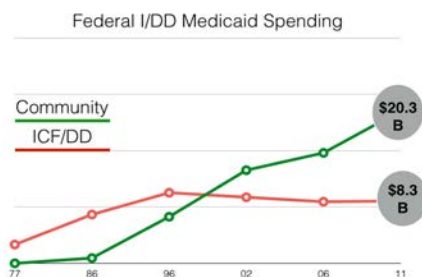
Flexibility. Support for a good life means moving with people like an ice dancing partner. There are ups and downs and risks. There are periods of discovery that involve trying new things in new places. There are occasions when a person needs more support or less support. Mutual agreements that allow adjustments to what, when, where and how much assistance a support worker provides build strong relationships.

Opportunities to learn. The heart of good support is skillful assistance. Some of this is direct –responding well when PTSD interrupts. Some of it involves negotiating the accommodation a person needs to be successful at something she wants to do –modifying a job procedure so a person can be successful at work. Much of this learning comes with guided practice, some from consultation with experts, some from more formal study.

Opportunities to reflect and deepen understanding. Transactions are regulated by policies and procedures and schedules. When these are skillfully crafted and wisely administered they coordinate activities, provide boundaries that reduce the chances that things will go wrong and offer some protection if they do. It's another matter to develop capacities to live a good life. Good support is a co-creative relationship guided by a shared understanding of what is important to and important for the person, a shared vision of a good life, and an understanding of the values that make it possible for people with developmental disabilities to resist the social forces that limit their full participation in community life. This calls for regular chances to reflect and plan.

Good ways to deal with personal conflicts. Support relationships can be complex and personal boundaries can need adjusting. There are times of stress and heightened emotion that strain relationships to the point of breakdown. What matters to and for the person takes priority, but a good relationship also takes account of what the support worker needs to be at their best. The purpose is to assist a person to live a good life but there can be conflicts between a person and family members about what a good life is – for example, how much risk is acceptable in a particular situation. It's important to respect choice, but what if a person's choice seems morally wrong to the support worker? Sometimes trust breaks down. Good relationships sometimes need mediation.

A changing environment squeezes investments in good relationships

Federal I/DD Medicaid Spending

Community
ICF/DD

$20.3 B
$8.3 B

77   86   96   02   06   11

Between 1977 and 2011[*] US Federal investment in long-term care for people with developmental disabilities grew significantly. The number of people with developmental disabilities who count on Medicaid increased by more than 60% and the balance of investment shifted from institutional settings (funded as ICFs/DD) to local service seatings (funded by Home and Community Based Services Waivers). Typical numbers of people living together in residential services shifted to groups of six or fewer.

Until around the turn of the century, state systems and services funded by HCBS waivers could largely manage their own approaches to assisting people. There were limits on the amount of public money available. There were regulations to comply with and plans and reports to file. There were limits on the number of eligible people who could receive services. There was significant variation across systems in the way services were designed and offered and the extent to which people were institutionalized. This was especially the case in Wisconsin, where County government held primary responsibility for orga-

[*] See *State of the States in Developmental Disabilities*. www.stateofthestates.org

nizing and managing human services. But the DD system and its providers had considerable autonomy within these limits.

The families of people with developmental disabilities were well organized politically. The field was energized by the work of deinstitutionalization, and special education, and new approaches to the development of young children with disabilities, and supporting adults at work. If system managers wanted to they could usually maintain strong boundaries around the DD system.

Most services were provided by non-profit organizations which were typically locally focused and locally accountable, usually to boards with a specific interest in developmental disabilities. Only a few organizations were statewide in their reach. Service planners became adept at supplementing HCBS rates with other resources, including Medicaid Personal Care and other Medicaid services. Service managers who chose to could manage their organizational boundaries to support innovations in personally tailored supports and investments in the conditions for developing good relationships.

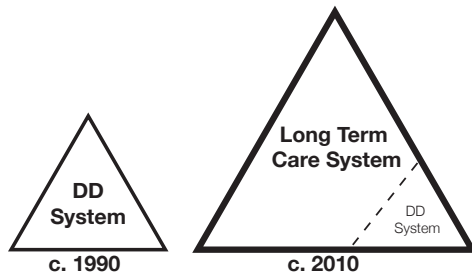As the 2000's passed, the environment changed.

- The federal Centers for Medicare and Medicaid Services (CMS) offered greater flexibility and attached more conditions to HCBS waivers. The variation in services across Wisconsin Counties was defined as producing unacceptable inequity. CMS increased its demands that the Department of Health Services be accountable for statewide compliance with its required assurances. State defined requirements for federally defined approaches to quality assurance, payments, safeguards, assessment and individual planning have increased markedly.

- Advocates formed alliances to focus on reducing numbers of people waiting for services and county to county variation in the extent and type of services available. Eliminating waiting lists became a priority.

- In the mid-1990s Wisconsin became an early adopter of what is now a national trend: the idea that long-term supports should be funded and regulated through a care-managed system with capitated rates. After pilot efforts that began in 1999, this system has grown to cover most of the state. It is designed to offer…[*]

  … entitlement to a variety of long-term care service for those eligible: no more waiting lists.

  … "a tailor-made package of services designed to meet [each eligible person's] unique needs and preferences".

  … funding that follows a person across service settings and county lines.

  … a simpler system that offers greater choice, with fewer cracks to fall through.

  … an affordable long-term care system.

- The Federal Government has increased its effort to enforce the Americans with Disabilities Act, particularly as interpreted by the US Supreme Court in the Olmstead decision (1999). In some states the Department of Justice has heightened its scrutiny of the way services are offered. In January of 2014, CMS issued rules defining 'community based settings' and specifying in detail the form and process for person-centered planning.

Any public policy involves trade-offs among important values. These environmental shifts are no exception. There are advantages to people. Eligible people and families waiting for necessary services have felt immediate relief. People continue to move out of nursing homes and some elders who are admitted to residential services are spending less time there because they stay at home longer. There are more options for people to self-direct their assistance.

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[*] Wisconsin Department of Health Services. *Why people with developmental disabilities need family care.* www.dhs.wisconsin.gov/familycare/history/whydd.htm
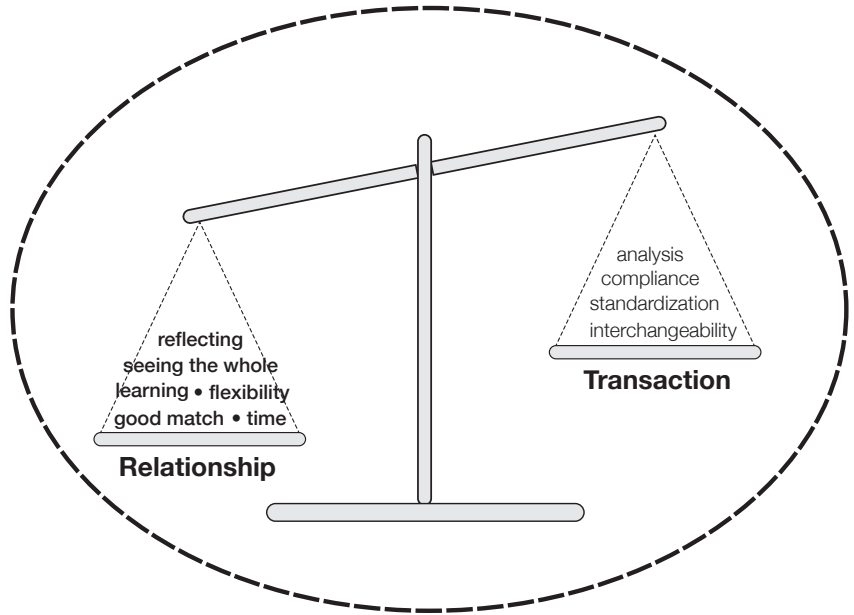
As the DD system loses autonomy, the balance tips…*

DD System — c. 1990

Long Term Care System / DD System — c. 2010

There are also risks to people with developmental disabilities and their families. These risks show up as system wide changes tip the balance in favor of managing transactions and reduce the space for relationship. This will shrink the numbers of people with good support for valued experiences to those whose families and friends have the resources to provide what's necessary.
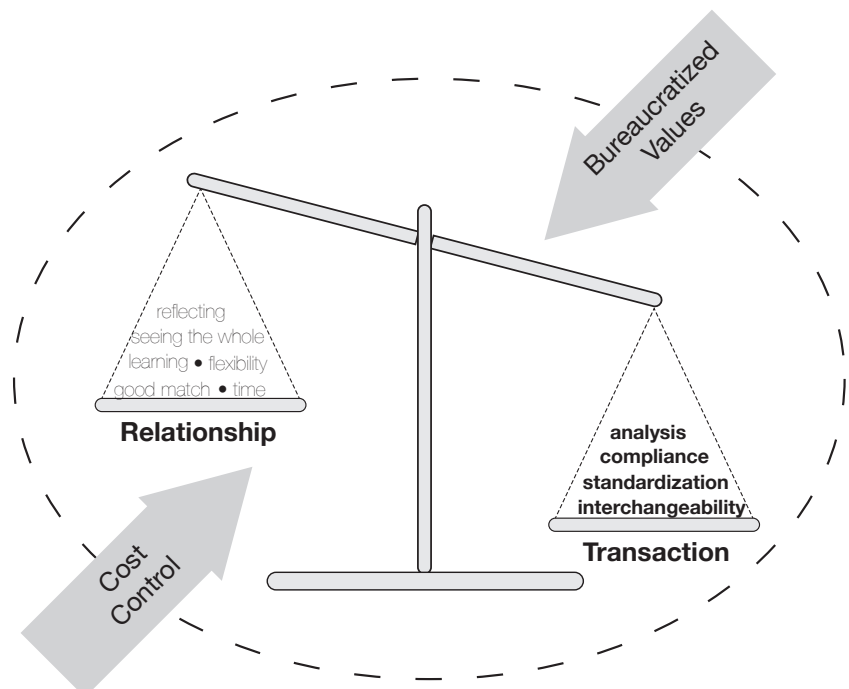
…from:

- Stronger system and organization boundaries
- Flexibility with available funds
- Capacity to invest in the conditions for good support
- Greater possibilities to support valued experiences

reflecting
seeing the whole
learning • flexibility
good match • time
Relationship

analysis
compliance
standardization
interchangeability
Transaction

…to:

- Greater influence by funding & regulatory bodies
- Less flexibility with available funds
- Less capacity to invest in the conditions for good support
- Decreasing opportunities to support valued experiences

* Focus on relationship and support for valued experiences has never been universal or even widespread. The point is that the current environment makes it even harder to stick to an organizational commitment to relationship.

reflecting
seeing the whole
learning • flexibility
good match • time
Relationship

analysis
compliance
standardization
interchangeability
Transaction

Bureaucratized Values

Cost Control

10

Reaching for easy answers

Not enough money
Too many people
Not enough help
Too many promises
Tough questions
Too little knowledge

The long-term care system is over-committed. There is already a shortfall of money and people to provide assistance that will become acute as more and more people become eligible. The system has made commitments to control costs and produce values (such as employment) that are well beyond its current capacity to deliver reliably at the scale of the whole system. The political climate is unfavorable to serious and sufficient engagement with long-terms support issues. The whole system is stressed and anxious and vulnerable to grabbing easy answers.[*]

Easy answers come from stories that frame issues as purely technical. Getting the level of public investment right is a matter of actuarial computation. Professionals can assess need and agree on mutually satisfactory outcomes and services in a few hours of meetings conducted according to a manual. As I infer it, the technical story about long-term care goes like this.

People need long-term care because they are incapable of performing activities of daily living. Long term-care efficiently and cost-effectively performs the specific tasks that people have proved that they can not. These tasks are specified in a plan that links objectively assessed incompetence to procedures that are well defined for efficient performance.

Whenever possible long-term care is delivered in a person's family home, especially when family members and friends can provide unpaid assistance. As need becomes more intense people move into specialized settings: assisted living, group homes, nursing homes.

This story keeps people busy finding answers to important technical questions. How will people be assessed? What level of incompetence makes a person eligible? What human resources practices best recruit and retain

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[*] This paper asks you to imagine that a whole system can have prevailing moods and emotions that affect the organizations and people that make up the system. Imagine that whole organizations can respond to stress and anxiety a bit like people do.
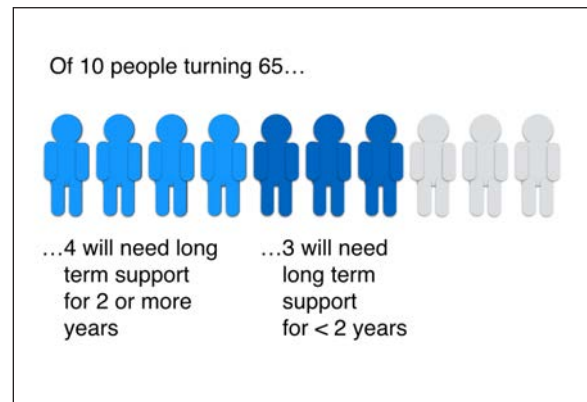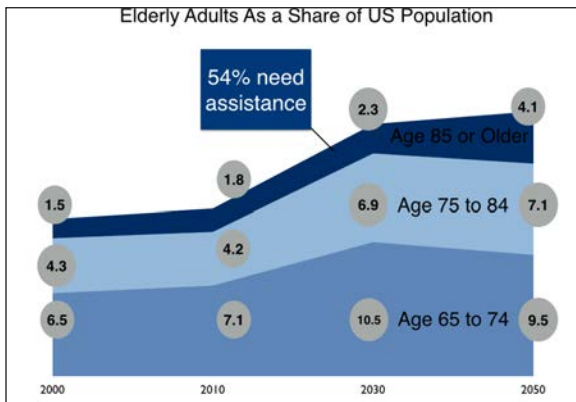
direct support staff at near minimum wages? What is the most efficient way to administer a bath? These are good and necessary questions and an easy answer can demand a lot of creative problem solving and managing. What makes it easy is that it treats assistance as if it were the product of a machine. Machines can be astonishingly complex and beautifully functional (look at your smart-phone), and best of all they can be engineered, manu-factured, and marketed through well managed process-es. They fit an attractive pattern of thinking: analyze the system, define the problem, develop options, choose the most cost effective, deliver the solution, continually refine and improve.

For shorthand, call this story of assistance to people with de-velopmental disabilities after the gears that mesh in a beauti-fully engineered machine. Call it a story of cogworld.
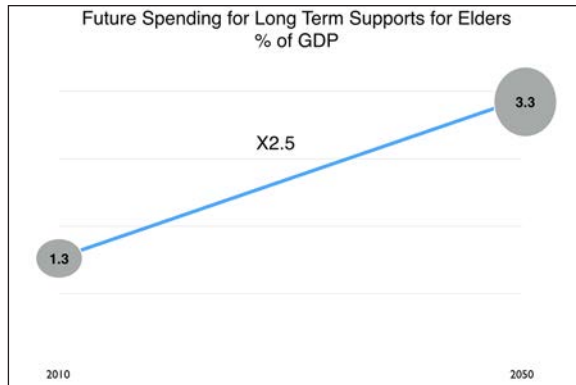
In uncertain times Cogworld can be an appealing place for managers and policy makers to hang out. The fac-ing page identifies some of the perceptions that lead the system to fear a tsunami of demand for long-term care among elders and reinforce the attraction of the cogworld story.[*] Political controversy over the growing claims of the Baby Boom generation on social security and healthcare has made long term-care for elders the focus of efforts to redesign long-term care. The assumption is that long-term care is long-term care; what works for elders will work for people with developmental disabilities. In practice that is a shaky assumption because the cogworld story of long-term care, which might make sense for elders, is a poor fit with supporting good lives for people with developmental disabilities.

Imagining support as the uniform outcome of a well en-gineered production system creates an expectation of
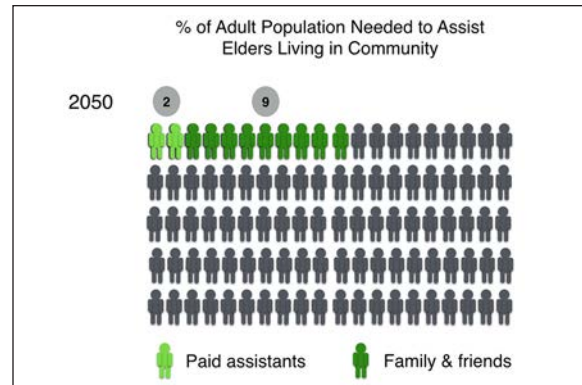
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* These charts are based on information from Congressional Bud-get Office (2013). *Rising demand for long-term services and sup-ports for elderly people.* www.cbo.gov/sites/default/files/44363-LTC.pdf and Robert Wood Johnson Foundation (2014). *Long-term care: What are the issues?* www.rwjf.org/content/dam/farm/reports/issue_briefs/2014/rwjf410654
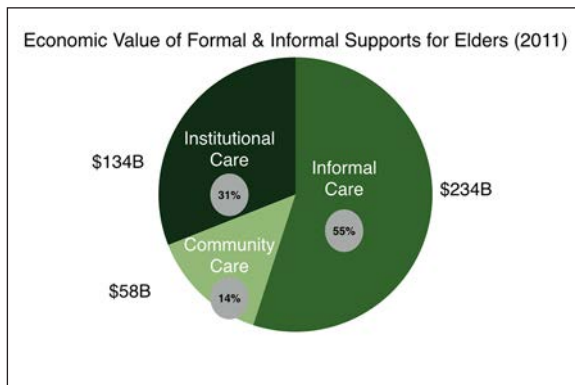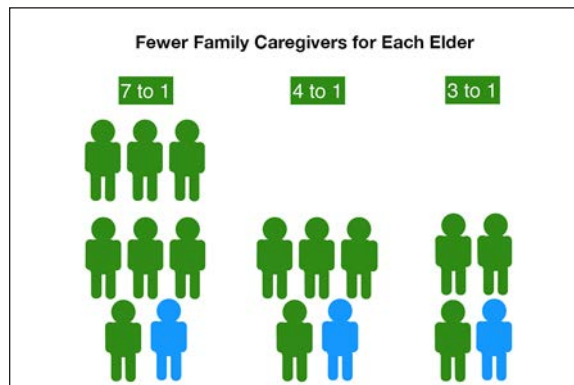
Elderly Adults As a Share of US Population

54% need assistance

Age 85 or Older

Age 75 to 84

Age 65 to 74

A lot more people will need services!

Of 10 people turning 65…

…4 will need long term support for 2 or more years

…3 will need long term support for < 2 years

Future Spending for Long Term Supports for Elders % of GDP

X2.5

It's going to cost a lot

% of Adult Population Needed to Assist Elders Living in Community

2050

Paid assistants   Family & friends

It's going to take a lot more of the workforce

Economic Value of Formal & Informal Supports for Elders (2011)

Institutional Care $134B — 31%

Informal Care $234B — 55%

Community Care $58B — 14%

People's families have to come through…

Fewer Family Caregivers for Each Elder

7 to 1   4 to 1   3 to 1

…but there will be many fewer of them

Fiscal Cliff Deal Repeals CLASS Act, Creates Long-Term Care Commission

Long-Term Care Panel Releases Recommendations But Fails To Offer Plan To Help Pay For Services

In divisive Washington, commission punts on long-term care

Politically, we're stuck

ELDERS!

control and managed efficiency. This underwrites two influences that reduce capacity to develop and sustain good support relationships and tip the balance toward managing transactions. These influences are: mechanistic strategies for managing scarcity and the bureaucratization of values through regulation.

Cost control. From the point of view of assistance for elders there are a number of sensible ways to control the rate of growth for long-term care costs. Nursing home costs are high and growing. More and more elders see out of home placement as a last resort and want to avoid it. Advising people to plan ahead for long term care needs, tightly controlling eligibility for public funds, encouraging family members to provide as much unpaid help as possible and connecting with community resources reduces demand for publicly funded long-term care. Assuring early and coordinated access to health care, providing targeted in home assistance with daily living tasks delays utilization of more costly settings. Guiding people to a continuum of residential care options –affordable assisted living and group homes- defers admission to high cost nursing homes.

There is room for argument about each of these elements. What level of incompetence, impecuniosity or isolation will qualify people for publicly funded assistance? How much should families be expected to contribute and what if they refuse? Will limits on the extent of support people can get at home push people into nursing homes? But overall, they might be a foundation for assistance acceptable to elders.

Within this strategy, a cogworld approach to cost control demands for efficiency at the price of flexibility by driving the system toward…

…assuring eligibility and justifying allocations by establishing objective, standard measures and regularly subjecting people to repeat administration of them by trained and tested screeners.

…plans that define assistance primarily by a tight link between assessed incompetence and highly delineated tasks and protocols.

…controlling self-directed budgets by imposing detailed specification and monitoring of allowable expenditures.

…defining assistance tasks in detail, restricting the places where they can be performed and requiring standard performance, sometimes including time specifications.

…assuming that it is efficient to regularly demand lower prices for assistance and that tasks can be performed interchangeably by any provider or assistant that is willing and qualified according to system management criteria; continuity of care means continuity of task per-formance, not continuity of relationship.

…allocating costs to tasks in small increments and demand-ing detailed reporting so that costs can be analyzed.

…tying reimbursement to direct, face-to-face contact without building adequate investment in training, super-vision and development into the rate.

…imposing (de-facto) caps and other conditions on direct support wages or costs of administering increasing requirements.

…proscribing expenditures, for example on communi-cation or mobility devices, and demanding extensive justification for exceptions.

…rigorous and repeated auditing by different authorities of compliance with detailed requirements for documen-tation.

…favoring the assumption that fewer, larger organiza-tions can deliver equivalent services more cheaply than smaller more local ones (*economy of scale*).

These measures are justified with the mantra that the sys-tem must be accountable to the taxpayer. This reasonable idea becomes a problem when it stops discussion rather than beginning an inquiry into what taxpayers actually want from their long-term care system. While it may be

that a majority votes against increased taxes overall, those are not necessarily votes against increased investment in long term care or in favor of entangling recipients of long term care in a skein of red tape that, in itself, drives up the cost of care.

It has become increasingly common to assume[*] that a managed market in long-term care offers the best alternative for funding services. States shift risk and responsibility for compliance with assurances of quality) to economically motivated care management entities. A capitated rate set by actuaries experienced in health care creates the conditions of risk and reward necessary to drive continual improvements in efficiency. Service providers gain an advantage by belonging to a managed network and compete to assist eligible people based on organizational capacity to deliver services deemed cost-effective and comply with applicable rules.

The trend to contain Medicaid costs by rolling together management of primary and acute care with long term care and manage it under a single rate seems unlikely to correct the balance of transaction and relationship.

Bureaucratization of values. Cogworld is a confident place. In that world, where more and more public officials take up residence while they are at work, well established practices of management command and control will efficiently produce any value and there are few if any conflicts or trade-offs among values. Those who think in cogworld terms have no trouble promising the simultaneous production of many valued qualities while containing costs.

- There will be no waiting for services.
- People will be healthy and safe.

The issue we confront in human services is one of fundamental human values– freedom and community. Yet, our hopes and plans for securing these values for everyone are invested in government agencies and public laws, in an approach that codifies and mechanizes the "delivery" of values. In holding to our hopes, we have seriously overestimated the power of bureaucracy.

–Burton Blatt[*]

[*] The efficiency of a managed market in long-term care has become an article of faith, especially among those ideologically committed to markets and shrinking the state. However it remains to be tested over time and at a large scale. It has proven tricky for several MCOs to manage the financial risk involved in a way that allows them to continue in business. Many details –such as rate setting– remain to be perfected. As well, effects on such important public policy goals as support for employment for people with substantial disabilities have yet to be fully evaluated.

[*] (1981). Bureaucratizing values. In J Joffe & G. Albee (Eds.). *Prevention through political action and social change.* Hanover, NH: University Press of New England, p. 38.

- There will be equity: people with similar eligible incompetencies will have access to equivalent types and quality of service regardless of where they live.

- Assistance will be person-centered and delivered in accordance with a person-centered plan that reflects the person's preferred outcomes.

- People will benefit from natural supports (cogworld speak for unpaid personal assistance from family and friends).

- People will have the option to self-direct their assistance.

Values are bureaucratized when a system's management controls their definition and implements measures to assure their production. In cogworld, values can be produced like the customer delights scripted by Disney's park experience designers. The means of value production include…

… defining the value in a rule, mandating compliance and seeking quantitative measures (*If you can't measure it, you can't manage it*) .

… contractually requiring policies and procedures that specify in detail how staff will construct values regardless of situational and individual differences.

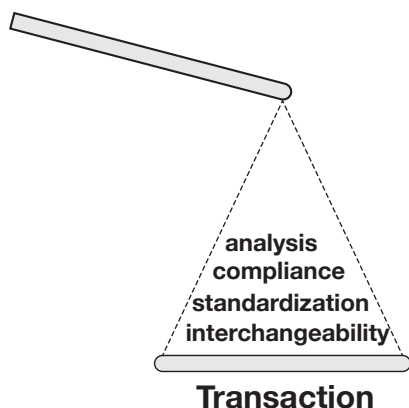…requiring training in how to comply with rules and regulations.

… calling for documentation and data that demonstrate compliance (*If it isn't documented correctly, it didn't happen*).

… inspecting to check compliance.

… requiring correction in cases of non-compliance.

… threatening to impose fines for non-compliance and making payments or license to operate contingent on compliance.

Advocates encourage the bureaucratization of values when they are successful at persuading legislators, judges and funding authorities to require the production of

Transaction

analysis
compliance
standardization
interchangeability

values like most integrated, least restrictive settings or person-centered services.

Negative effects. A cogworld approach to managing costs and manufacturing values increases transaction costs. Increasing amounts of time and money go into activities like internal checking and rechecking to assure that billing codes will be read as correct and required documentation will pass external inspection. The point at which increased expenditure on compliance ceases to benefit people is easy for cogworld to overshoot.

Cogworld promises can damage the resources necessary for collaboration. Because the system defines the values it promises to manufacture, conflicts can develop. A person who understands the promise of "no waiting for services" as "finally, I can move out of my parents home and get the assistance I need to live in my own place" will be puzzled if the people charged with developing her person-centered plan parse this into "long term care needs and outcomes" and "wants and personal outcomes" and then guide her to the service their system has decided is the cost-effective way to meet her long term care outcomes: staying in her parental home. This provides a sobering lesson in who defines the boundaries of expectation are and who controls the means to implement one's choices.

Cogworld has a powerful influence on the quality of attention that people with developmental disabilities experience from the people they rely on for assistance. Values and goals are defined externally, in the system's terms and through system prescribed processes. The system's voice is not just one important influence, it dominates others by absorbing the often messy and conflicted concerns of fragile, fallible and magnificent humans and reframing them as outcomes the system can produce technically to standards the system can impose and enforce.

Values, including best use of public funds, become a matter of compliance. This effectively promotes compliance to top value. It is harder to struggle for a deeper practical

understanding of standards like least restrictive, most integrated alternative, when the system demands attention to compliance with the state's CMS approved definition of a community based setting. There is less energy for taking the challenge of learning with a person how to increase their capacity for self-regulation and personally meaningful activity when the system will impose punishment if the person's file lacks a Behavior Plan documented in the prescribed format. When failure to completely answer all of these compliance questions brings the additional bureaucratic work of producing and reporting on plans of correction, attention shifts even farther away from collaborative work with real people.

The dominance of extrinsic motivation makes Cogworld a demoralizing place to work for people who are intrinsically motived by meeting the challenges of relationships that strive for equality and support people's striving for a good life. Cogworld's engineers acknowledge what they call the "workforce problem". Diminished political imagination frames the solution as treating workers like low skilled, interchangeable parts in a machine that cranks out tasks done to spec. The resulting care machine counts on economically motivated managers to assure quality performance at an affordable cost without very significantly increasing wages and benefits. This technical fix heavily discounts the commitment to relationship that the best direct support and professional workers have brought to their work. It leaves committed people feeling that they are becoming someone they did not want to be when they chose to work with people with developmental disabilities. Those who are committed may keep absorbing demands that offer no real benefit for the sake of their relationships, but this seems exploitive and unsustainable.

Cogworld is hungry for stories that justify more rules. Stories about misuse of funds, often retailed like ghost stories to entertain cub scouts, preoccupy the system with finding fraud –an enterprise made easier by combining

rigid and detailed expenditure controls with counting reporting errors as fraud. System managers accumulate requirements on the assumption that compliance serves positive values and can be digested by providers without reducing the quality of their assistance. Often this assumption is accompanied by another: that no additional funds are required to meet the costs of compliance. In a market controlled by a single purchaser, its difficult to pass costs of compliance back to the customer as long as another provider is available to assist people more cheaply.

The logic of contracting tempts system managers to abdicate responsibility for joining in solving problems and developing innovations that demand high levels of collaboration and shared learning. In cogworld requiring performance in a contract is the same as solving a problem.

The danger of a single story

The cogworld story of long-term care and the cost management and the value production measures that flow from it may fit the situation of elders reasonably well, I leave it to them to comment. The cogworld story is gaining in power and, as its influence grows, so does the clash of stories. The cogworld story, which slips the system into mechanistic answers, contrasts with a story of balance that demands co-invention of ways to manage scarcity, safeguard people and promote development that are adequate to the demands of the times.

The threat in the cogworld story is its tendency to drown out more complex and interesting stories of good support. It appeals to a common desire to engineer technical solutions and avoid the messiness and uncertainty of human beings adapting to their frailty, interdependency and vulnerability in a world that is changing rapidly and unpredictably. To keep cogworld from colonizing people's lives we need to live a story of balance.

The Cogworld Story	A Story of Balance
People need long-term care because they are incapable of performing activities of daily living. Long term-care efficiently and cost-effectively performs the specific tasks that people have proved that they can not. These tasks are specified in a plan that links objectively assessed incompetence to well defined procedures. *Whenever possible long-term care is delivered in a person's family home, especially when family members and friends can provide unpaid assistance. As need becomes more intense people move into specialized settings: assisted living, group homes, nursing homes.*	*People with developmental disabilities require life-long assistance in order to meet their responsibilities and exercise their rights as citizens. A personally tailored combination of technology, accommodation, specialist service and personal assistance enables them to develop and engage their capacities. Each person and their family and allies deserve a strong voice in the way opportunities for a secure home, meaningful relationships and contribution are discovered and necessary assistance is designed and delivered. Effective supports will be individualized, flexible and oriented to active inclusion in community life. The quality of support is founded on good and growing relationships with the people who offer it.*

The story of balance recognizes three simple realities that generate a variety of possibilities so complex that they can only be addressed in the context of personally tailored supports.[*] First, people with developmental disabilities value the same experiences as anyone else: good relationships, the respect that comes from participating in valued social roles, the chance to pursue personal interests in community life, opportunities to develop individual capacities and make a contribution, and the freedom to establish a secure home and do meaningful work. Second, more people with developmental disabilities will have these experiences when the tasks of assistance are capably performed by people who are supported to develop and sustain good relationships. This demands a dynamic balance of the relationship and transactional aspects of the work. Third, our statements of what we value in assisting people with devel-

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* Dane County, WI has developed a system with the capacity to personalize supports and manage costs through a combination of multiplying resources and allocating available funds through individual budgets. For a current account of international innovations that provide alternatives to the most common implementations of managed care see Simon Duffy, *Traveling Hopefully: Best Practices in Self-Directed Support*. http://goo.gl/Xvmjsj.

opmental disabilities exceed what our system can reliably deliver. We can only deliver on the promise of equal citizenship if growing numbers of people with disabilities and their families join committed assistants to discover what works for them as whole people in real places.

People with developmental disabilities and their families know from history and experience the profound limitations of living under the regime that the cogworld story imposes on them. They know that these bureaucratic simplifications are not the way to a good life as a contributing citizen: definition of long-term care as primarily prosthetic aid for incompetence in activities of daily living, assistance restricted by narrow time, space and task boundaries complex rituals of detail compliance with regulations and eligibility requirements, long-term reliance on families as primary providers of housing and assistance, inadequate pay and support for direct support workers, and congregation of people into groups on the basis of clinical assessment of need and managerial assumptions about efficiency. They know that commitment and relationship are fundamental to good support for a life a person has good reasons to value living.

The developmental disability status recognizes a life-long need for well organized assistance. It might be reasonable to expect family members to assist an elder to stay in their own family home for a few years with limited public investment. It is another matter to expect families to assume primary responsibility for housing and assistance for 30 to 60 years. Many elders might be well served by carefully bounded paid help with activities of daily living, especially if it comes from reliable and courteous caregivers. Most people with developmental disabilities benefit most from relationships that offer good support for developmental growth and contributing citizenship. Many disabled elders have homes of their own and a rich history of playing a variety of valued social roles. Many people with developmental disabilities need good support to establish and

maintain themselves at home and in valued social roles for the first time.

The assistance that people with developmental disabilities require is effective to the degree that it is tailor made and remade to fit each individual, developing person. Standardized services operated by interchangeable hands for groups limit people's potential and, typically, exclude them from full participation in community life.

The challenge

Keeping space open for the further development of long-term support based on the story of balance that reflects what people with developmental disabilities and their families and allies have achieved over the past 50 years is the challenge for this generation.

The cogworld story of long-term care as a bundle of transactions that cranks out values by following detailed rules easily becomes self-sealing. The machinery of cogworld lacks a reflective function to question the way it effects people. Failure to reduce the rate of growth of costs proves the need for more control and larger scale. Errors in compliance demand more rules, more training, more inspection.

One step toward meeting the challenge is for people to make time to reflect and notice the growing imbalance in our system. The tools of cogworld have enabled us to dig ourselves into a deep hole. Change begins when we notice this, stop digging and begin to co-create new ways to approach scarcity and the creation of value.

Those of us who hold management responsibilities can exercise continence. In a hierarchy there is pressure to add an a just-in-case factor to interpretation of the requirements flowing downwards. State managers add extra requirements and restrictions to federal requirements to decrease the chances of non-compliance. Service organization managers repeat the pattern. By the time policies reach those who are closest to people they have

become unexplained and inexplicable restrictions that people are told to do because unspecified woe will fall on the non-compliant. A careful audit of what the rules actually require may loosen strictures and raise the possibility of questioning policies that disadvantage people.

The conditions of demand that have drawn our system into cogworld must be met. If we do not want to live in cogworld we must invent new ways…

…to deal with demands for assistance that are very almost certain to rise faster than the rate of public investment.

…to safeguard vulnerable people and strengthen their voice and autonomy, including their capacity to take responsibility for effectively directing their supports.

…to honor and generously support the contributions that families make through the life cycle.

…to build and sustain an adequate number of good relationships to form the medium for good support for each person.

…to embed people with developmental disabilities in community life by encouraging the arts of mutual accommodation.

…to successfully advocate for a new social settlement for long-term support that does not define developmental disability as a medical condition or a deficit in ability to perform activities of daily living but views publicly funded assistance as a necessary support for active citizenship.

People with developmental disabilities and their families and allies have made real progress toward meeting each of these demands.

Breaking out of cogworld and bringing relationship and transaction into a healthy balance is the work of free, conscious people who choose to work together.

Progressive service providers and system managers have found ways to survive that allow continued development.

What is in doubt is how many of these social inventors will have the free space necessary to continue to hold relationship and transaction in a productive tension. Holding this space calls on us to face our social and cultural fear of dependency in a creative way.